New York State Department of Health
2002 Long Term Care Initiative

Executive Summary

Concomitant with Governor Pataki's initiative to plan for the needs of New York's aging population, steps are being taken to assess the long term care system in New York State. As one part of this process, in 2002, the New York State Department of Health (DOH) examined reports on long term care, examined reforms in other states, and solicited input from concerned major stakeholders.

Specifically, the Department held in-depth interviews with a number of stakeholders, as well as held public forums to obtain advice on critical long term care issues facing New Yorkers. The meetings took place in Chautauqua, Clinton, Erie, and Westchester Counties and in New York City. Over 200 consumers, providers, advocates, and representatives of state and local government participated.

The interviews and forums offered stakeholders an opportunity to express their thoughts on the most important issues in long term care today and for the future. Six major themes emerged:

- Public Education: Elected officials, policy makers and the public must be educated on the impact the aging baby boomer population will have on the future demand and cost for long term care services.

- Personal Responsibility: New Yorkers must assume more personal responsibility for planning and paying for their long term care needs. The growing dependence on government funding must be curtailed.

- Realignment and Better Coordination of Funding: Commercial, public and private funding in the long term care system must be realigned and better coordinated to improve the effectiveness, accessibility and availability of services and to eliminate the fragmentation and duplication of services that currently exists.

- Point-of-Entry: Individuals and their families need a community-based point of entry to the long term care system that offers: a uniform process for assessing personal long term care needs, assistance in the development of care plans, information on services available in the community, and referrals to a choice of appropriate service providers.

- Workforce Development: Current long term care staffing shortages must be addressed and the work force developed to meet the anticipated need for services over the next several decades.

- Regional / local flexibility: Any redesign of the long term care system must be done in a way to afford regional and/or local flexibility in administering services and programs.

As the largest single payer of long term care services in New York, the State Medicaid Program will take this timely and important advice under consideration. State and local government leaders, together with other concerned groups, must also play a leadership role in shaping a shared vision for restructuring the system and in garnering the support necessary to implement needed change. Working in partnership, these stakeholders can affect an evolution of the long term care system, over the next decade, to meet the needs of all New Yorkers.

Introduction/Background

As a result of both the growing dependence on government financial support and the increase in demand for long term care services, legitimate questions exist about the ability of the current system to meet the future needs of New Yorkers.

Under the leadership of Governor Pataki, efforts are underway to assess the long term care system in New York State. As part of this process, the New York State Department of Health determined that it needed to identify what does and does not work in today's long term care system and to obtain advice on changes to be considered for the future.

The scope of the review included examining reports on long term care issued during the last twenty years (Attachment 1), examining reforms in other states, and meeting with a diverse mix of major stakeholders concerned about long term care.

For purposes of this initiative, long term care services were defined as the array of services designed to support the chronic need for assistance with activities of daily living, including medical and social supports. These services can be provided both in nursing homes and in community settings.

In 2002, meetings, in the form of interviews and forums, were convened with representatives of local departments of social services, aging, mental health, and public health; hospitals discharge planners and other providers; advocates for individuals with disabilities; and other groups interested in long term care. These meetings were arranged with the assistance of the Commissioners and Medicaid Directors of local departments of social services, who were requested to engage a cross section of representatives from government, and the provider and advocate communities. The interviews and forums took place in Clinton, Chautauqua, Erie, and Westchester counties and in New York City.

Over 200 individuals participated—including persons with disabilities, parents of adults with disabilities, children of aging parents, patient advocates, long term care providers, representatives of provider associations, and representatives of state and local government—representing a broad spectrum of stakeholders very interested in and concerned about long term care (Attachment 2).

Statements and assumptions describing current issues in long term care developed by the DOH Office of Medicaid Management and selected county Medicaid Directors were distributed to all participants. These documents (Attachment 3) were used to start and guide discussions, resulting in an opportunity for stakeholders to express their thoughts on the most critical long term care issues facing New Yorkers today and for the future.

Six major themes emerged.

1. Public Education: Elected officials, policy makers and the public must be educated on the impact the aging baby boomer population will have on the future demand for long term care services.

2. Personal Responsibility: New Yorkers must assume more personal responsibility for planning and paying for their long term care needs; and the growing dependence on government-funding must be curtailed.

3. Realignment and Better Coordination of Funding: Commercial, public and private funding in the long term care system must be realigned and better coordinated to improve the effectiveness, accessibility and availability of services and to eliminate the fragmentation and duplication of services that currently exists.

4. Point-of-Entry: Individuals and their families need a community-based point of entry to the long term care system that offers: a uniform process for assessing personal needs, assistance in the development of care plans, information on services available in the community, and referrals to a choice of appropriate service providers.

5. Workforce Development: Current long term care staffing shortages must be addressed and the workforce developed to meet the anticipated need for services over the next several decades.

6. Regional / local flexibility: Any redesign of the long term care system must be done in a way to afford regional or local flexibility in administering services and programs.

The supporting rationale for each of these recommendations follows.

Public Education

Stakeholders cautioned that elected officials, policy makers and the public should be made aware of the increasing need for long term care services suggested by population projections and the current trends in service use and public costs.

Demographic projections indicate that, by the year 2025, over 22 percent of New York's population will be aged 60 and over. This will represent a 40 percent increase in the population in this age group since 1995. As the baby boomer population ages, there is little doubt that the number of New Yorkers needing long term care services will increase. Aside from the trend for the increasing future health care requirements of an aging population, stakeholders suggested that elected officials and policy makers need to be made aware that long term care is not solely for the elderly and includes younger individuals with disabilities seeking care in the community. Future planning needs to consider the entire population.

Home and community based waivers and other state funded grant programs have grown over the past decade, making it possible for persons with disabilities of all ages to remain in community settings. Enrollment in these programs and the range of provided support services has grown. As a result, New York's State and local budgets support the largest home and personal care program in the country.

Recommendations:

- Consider demonstration programs to give local officials and providers an opportunity to learn about models for long term care that address the community needs of all individuals with disabilities, regardless of age.

- Raise awareness that Medicare does not pay for chronic long term care services.

- Carry out a public education program through which comprehensive information about likely needs, how to plan for and access needed services in their own communities, costs of care, and private insurance and other payment options may be distributed.

Personal Responsibility

Stakeholders discussed the urgent need for the general population to recognize that tax-supported programs cannot keep pace with the future demand for long term care. It was acknowledged that many consumers expect government to pay for unlimited services. However, as demographics shift to swell the population most likely to require these services, New Yorkers must assume more personal responsibility for planning and paying for their own needs.

Medicaid, the program originally designed to provide for the medical needs of the financially needy, can now be accessed by those who can manage their family assets to meet the program's financial eligibility standards. In fact, current regulations intended to prevent improvishment or other family hardships can be manipulated to ensure a family's qualification for Medicaid beyond the program's intended mission. There is widespread perception that this practice is supported through a vast network of elder law consultants and financial planners.

Many stakeholders suggested legislative and regulatory reform to eliminate opportunities for unnecessary and inappropriate reliance on Medicaid. They advised changing the law related to the transfer of personal assets and the ability of an individual's spouse to refuse to contribute toward his/her cost of care. They also recommended new legislation to eliminate statutorily-driven inequities between nursing home and home care settings related to eligibility provisions regulating personal asset transfers.

Some stakeholders went so far as to say that planning for long term care should not be optional. There are over three million residents of New York State who are over age 60, yet less than 200,000 long term care insurance plans have been sold to date. Accordingly, personal responsibility could be enhanced by increasing awareness about long term care insurance options.

The NYS Office for Aging indicates that 75 percent of all long term care is provided by informal caregivers, but that often this important resource is not recognized in the planning process. Stakeholders acknowledged that an individual's informal support system should be considered as an important factor in personal long term care planning. The participating stakeholders noted that it is imperative that government rebalancing efforts include innovative approaches to support this great resource of unpaid care as it is critical to delaying an individual's reliance on Medicaid.

Recommendations:

- Amend New York State laws to establish standard eligibility rules to promote responsible requests for Medicaid services.

- Enhance the general population's familiarity with available long term care insurance products.

- Develop affordable, accessible long term care insurance and encourage its purchase with personal income tax and/or other incentives.

- Develop innovative approaches to support informal caregivers and lessen future reliance Medicaid assistance.

Realignment and Better Coordination of Funding

Medicaid is the single largest payer of long term care services in New York State. As New York has expanded the number of services available under Medicaid and various specialized federal Medicaid waivers, the number of eligible persons, covered services, and costs has increased dramatically. In 2002, total Medicaid expenditures for long term care services amounted to $8 billion. It is clear that, with the changing demographics, Medicaid will not be able to continue to bear the primary financial responsibility for this care. In fact, stakeholders reported that in some areas of the state, Medicaid budgets absorb 100% of property tax revenues—local governments are calling for fiscal relief.

Private and commercial insurance payers also support the cost of care for individuals with disabilities of all ages. Stakeholders indicated that, if effectively managed, the current level of funding paid by private, public and commercial payers today may be sufficient to meet the future cost of care. However, the current process whereby government and private administrators target specific individuals and programs creates a "silo effect" that prohibits maximization of available dollars. Better coordination of services and funding mechanisms could improve the cost effectiveness of provided care.

Lack of coordination also negatively impacts cost-effective planning in times of health crisis. Often, the consumers' first contact with the long term care system is the provider of an emergency service. Once a provider is engaged, the placement may continue

solely on the basis of expedient discharge planning, even though the consumer may be more appropriately cared for in a less restricted and/or less expensive and more preferable level of care. In this way, ease of placement becomes a disincentive to identifying creative long term care strategies.

Stakeholders also emphasized that a balanced system with coordinated long term care planning, service and funding must recognize housing, transportation and social services as critical supports for persons with disabilities in the community.

Recommendation:

- Assure the most appropriate and cost-effective care through improved coordination between providers and integrated funding streams.

- Remove disincentives to comprehensive individualized long term care planning.

- Fund community support services, such as housing, transportation and social services, through resources outside the Medicaid program.

Uniform Process at Point of Entry

Some stakeholders described a single point of entry for all long term care consumers as key to a successful county coordinated system. Others prefer a "uniform process" to ensure that the same information, assessment and referral services are available at any of the various system entry points (such as local government agencies, hospitals or other county contracted agencies). The overarching principle of this process is to provide uniform and unbiased information, assistance and choice for all consumers.

Stakeholders indicated that consumer treatment can vary depending on payer source and the extent of case managers' and discharge planners' awareness of available services. The impact of discharge planners on consumer access is particularly sensitive since fiscal constraints have reduced their numbers in the workforce and the resultant increased caseload ratios exacerbate variances in the availability of individualized assistance and planning. Similarly, cost efficiencies and reimbursement methodologies require hospital discharge planners to act quickly, often precluding their ability to effectively involve family members or other informal caregivers in the consumer's long term care planning process.

Recommendation:

- Develop a uniform system entry process whereby all applicants, regardless of payer source or provider can receive the same services: information, screening for need, assistance with developing a plan of care, and a choice of service options.

- Develop a long term care assessment process that emphasizes the involvement, input and commitment of all appropriate parties.

Work Force Development

Currently, both institutional and community-based care services are adversely impacted by the insufficient numbers of trained people in the health care workforce. Some stakeholders described the home care industry in certain regions of the State as “on the verge of chaos” because of labor shortages.

There is additional concern that some programs and services are inequitably directed to those who can privately pay, leaving the poor underserved. This situation may dramatically worsen as baby boomers, born between the mid-1940s to the mid-1960s, swell the ranks of the sixty and older population.

Stakeholders agreed that there is a great need to strengthen the health care workforce through improved educational opportunities, career ladders, worker benefits, marketing and recruitment, transportation and housing. They encouraged development of the non-traditional workforce through new training and employment programs for SSI/SSD recipients and other creative demonstration programs that would foster collaborative training efforts between the State and local school districts, colleges and universities in hard-hit regions.

Several stakeholders noted that use of new technologies may augment the medical workforce. Such measures could support and/or improve upon current methods of care yet reduce per-person costs. For example, advances in telemedicine could allow one off-site nurse to monitor the condition of several consumers; new inexpensive paging devices could be distributed to at-home patients to summon on-call responders when necessary.

<u>Recommendations:</u>

- Explore and pursue ways of strengthening the health care workforce, emphasizing creativity and collaboration.

- Conduct State pilot programs in diverse localities to test emerging technologies that have the potential to augment the health care workforce.

Regional and Local Flexibility

Governor Pataki has provided the leadership to improve the health care of New Yorkers in the expansion of the Child Health Plus program and the creation of the Family Health Plus program. He directed State agencies to participate in “Project 2015” to better understand and address the impact of the State’s aging population, and he is leading the way in other important State initiatives such as “NY Cares.”

Stakeholders emphasized that both State and local leadership is the key to success in redesigning a coordinated, responsive long term care system. They noted that some counties have already developed highly coordinated approaches for maximizing local long term care resources, and attributed the success of these programs to the leadership of forward thinking county executives and managers. For example, the Community Alternative Services Agencies (CASA) approach, implemented by several counties, was praised for effective pre-admission screening, referral and home care placement activities. It was stressed that such successful local efforts should be accommodated in any future system redesign.

However, stakeholders cautioned that even in the best situations, turf issues can result in funding silos and disparate service programs that are contrary to a truly coordinated system. Accordingly, State and local leadership must take the steps necessary to develop a uniform long term care system that will eliminate obstacles to cost efficient service, yet remain responsive to local conditions and resources.

Recommendation:

- Encourage cooperative efforts between appropriate State, county, provider and consumer advocacy associations in the redesign of the long term care system.

- Ensure that the long term care restructuring process is responsive to regional variances in services and demographics and includes opportunities for locally established best practices and administrative flexibility.

Conclusion

New York State has a long and proud history of providing for its citizens' long term care needs. Yet the consensus among stakeholders was that changes are needed to prepare the State's systems of care to meet the future needs of all its citizenry, regardless of age or disability. State and local governmental leaders, together with other interested stakeholders, must play a leadership role in creating a vision for rebalancing the long term care system and garnering the support to make needed changes. Working in partnership, these stakeholders can affect an evolution of the long term care system over the next decade, to meet the needs of all New Yorkers.

ATTACHMENT I

REPORTS ON LONG TERM CARE

The CASA Association of New York State, "Towards A Coordinated Long Term Care System", February, 1995.

Erie County Community Alternative Systems Agency (CASA), "The Unmet Needs Of Young and Middle Age Adults with Functional Impairments", Research Supported by the New York State Department of Health through an Innovative Home Care Grant, October, 1999.

Governor's Task Force on Long-term Care Financing, "Securing New York's Future: Reform of the Long-Term Care Financing System", May, 1996.

New York Association of Homes & Services for the Aging, "Assisted Living Reform, Accessibility, Affordability and Accountability", May, 2000.

New York State Department of Health, Office of Continuing Care, Post Acute Workgroup Report, Consumers Speak About Their Continuing Care Needs: A Report of Twenty Consumer Focus Groups, and Providers' and Other Stakeholders' Perceptions: "Achieving a Shared Vision for Continuing Care", January, 2000.

New York State Department of Health, Post Acute Workgroup, Consumers Speak About Their Continuing Health Care Needs, Long Term Care of the Aged and Disabled in New York, A Public Policy Framework, October, 1991, Alice P. Lin, DSW, Executive Chamber, Michael Dowling, Director of Health Education & Human Service, Executive Chamber.

New York State Health Planning Commission, Final Report: NYS Systems Development Project, March 1981.

New York State Task Force on Long-Term Care, "Reforming Local Access and State Structure for Long-Term Care in New York", January, 1993.

State Office for the Aging, Managing Access to Aging Services, January, 1991.

United Hospital Fund, "Medicaid Long Term Care in New York City: Comparing Needs and Personal Care Services in the Home Attendant Program and in Nursing Homes", February, 2002.

ATTACHMENT II

LIST OF PARTICIPANTS

Meetings with Other State Agencies:
State Office for the Aging (SOFA), First Deputy Commissioner Neal Lane
Office of Mental Retardation and Developmental Disabilities (OMRDD)
Commissioner Thomas Maul, Deputy Commissioner Alden Kaplan
Office of Mental Health (OMH), First Deputy Commissioner Sharon Carpinello
Department of Housing and Community Renewal (DHCR),
Assistant Commissioner Kevin Carlisle
Office of Temporary and Disability Assistance (OTDA),
Commissioner Brian Wing and staff
Vocational Educational Services for Individuals with Disabilities (VESID),
Coordinator for Government Programs, Douglass Bailey
Governor's Advocate for the Disabled, Greg Jones
Department of Labor (DOL), Directors Karen Papandrea and Margaret Moree

Meetings with Other Stakeholders:
NY Association of Homes and Services for the Aging (NYAHSA),
Executive Director Carl Young
Home Care Association (HCA), Executive Director Carol Rodat
The Eddy Northern Health (EDDY), Director Jo Ann Costantino
Schuyler Center for Analysis and Advocacy (SCAA), Executive Director Karen Schimke
Greater NY Health Association (GNYHA), Center for Continuing Care,
Executive Director Scott Armhein
Council of Senior Centers/Services, New York City, Director of Policy Bobbie Sackman
Alzheimer's Association NYC, Public Policy Coordinator Ann Berson
Clinton County Department of Social Service, Commissioner Jay LePage
Veterans Affairs Western New York Healthcare System, Director William F. Feeley
United Way of Western New York, President Arlene Kaucus
Continuing Care, Western New York, Executive Director Jim Totaro
Erie County Department of Social Services, Commissioner, Deborah Merrifield
Erie County Department of Social Services, Medicaid Director Christine Bush
Independent Living of Western New York, Executive Director Douglas Usiak
Westchester County, Three Parents
Westchester County Department of Social Services, Commissioner Kevin Mahon
Westchester Independent Living Center (ILC), Executive Director Joe Bravo
Westchester County Department of Social Services, Medical Director Steve Riordan
Westchester County Department of Social Services, Director Home Care Wendy DeMartis
Westchester Disabled on the Move, Executive Director Melyvn Tanzman and five relatives of seniors receiving LTC services
Chautauqua County Department of Social Services, Commissioner Ed Miner
New York City Human Resource Administration (HRA), Medical Assistance Program (MAP),
Deputy Commissioners Bridgette Simone and Mary Harper
Visiting Nurse Service (VNS) of New York City, Executive Director Carol Raphael
Young Adult Institute, Executive Director Joel Levy
Young Adult Institute, Administrator for Home Care Allen Rosen
25 Members of the New York City's Home Care Advisory Council

County Wide Meetings (average of 30 stakeholders per meeting): Clinton, Erie, Westchester, and Chautauqua Counties, and New York City.

ATTACHMENT III

DISCUSSION GUIDE STATEMENTS

The Department of Health's Office of Medicaid Management and selected county Medicaid Directors developed statements to capture emerging long term care policy issues. The statements were distributed to all interviewees and participants at the regional meetings and used as discussion starters. Participants were urged to focus on these issues or any other topics they viewed as important.

STATEMENT I: Consumer access to appropriate long term care services may require obtaining information about, applying for, and receiving services from a number of different programs and providers. At the same time, the consumers' needs, financial resources and medical and non-medical support must be assessed and services coordinated.

STATEMENT II: There are many factors that influence long term care service options, such as: hospital and nursing home discharge planning, safety/risk and housing and non-medical support.

STATEMENT III: Financing long term care is estimated to account for an increasing percentage of the Medicaid budget. As the demand for services increases, it must be determined how these services will be financed. Key topics for discussion include private pay incentives, long term care (LTC) insurance, other government payers including Medicare, Veterans Administration, Older Americans Act, and Medicaid. As the demand for long term care services increase, the impact of eligibility policies such as transfer of assets must be reexamined.

STATEMENT IV: Workforce availability can have a major impact on the availability of services as well as the quality of care. Regional shortages of professional and paraprofessional staff can influence service provision.

STATEMENT V: Information technology should be a valuable tool in the planning and operation of the long term care system.

STATEMENT VI: The changing demographics of the population and the long term care programs needed to address the present and future needs of consumers must be studied; the system may need to be restructured to accommodate changing needs.

DISCUSSION GUIDE ASSUMPTIONS

Prior to commencing the review, several assumptions about long term care were articulated and shared with all interviewed stakeholders to serve as a guide to discussion during interviews and regional meetings. The assumptions focused on anticipated interest in: public education; consumer, provider and government access to information and services; need for individual long-range planning; access to and provision of services in the least restrictive appropriate setting; coordination of services; and the means for meeting the cost of care.

The following assumptions were shared with all stakeholders interviewed and present at the county-wide meetings.

- It must be recognized that community integration in the least restrictive setting may be the appropriate choice for consumers.

- Future planning for long term care services must focus on personal responsibility and services that will enable consumers to remain in the community independently and delay entry into the long term care system as long as they desire and it is safe to do so.

- The public must be educated to understand that they have a personal responsibility to plan and provide for their future long term care needs and that Medicare does not cover extended long term care needs.

- Consumers and their families must have easy access to information about the long term care system in their communities.

- Policy makers, providers, government at all levels and consumers must be aware of the changing demographics and potential impacts of population changes.

- State and local government and providers and their associations must join together to build an infrastructure that better coordinates long term care services.

- Long term care planning includes individuals of all ages with disabilities.

- The goal of planning and coordination should be to maximize the consumers' quality of life.

- Individual long term care plans must balance personal risk and safety when considering the consumers array of services and location.

- Future planning for long term care must focus on coordination, elimination of duplication of services, personal responsibility and efficiency of administration in order to maximize available private and public funding.